

AMENDED IN ASSEMBLY JUNE 19, 2008

AMENDED IN ASSEMBLY JUNE 5, 2008

AMENDED IN ASSEMBLY MAY 22, 2008

AMENDED IN ASSEMBLY APRIL 7, 2008

AMENDED IN SENATE MAY 2, 2007

SENATE BILL

No. 527

Introduced by Senator Steinberg

February 22, 2007

An act to add and repeal Article 9 (commencing with Section 4699) of Chapter 6 of Division 4.5 of the Welfare and Institutions Code, relating to autism.

LEGISLATIVE COUNSEL'S DIGEST

SB 527, as amended, Steinberg. Autism Spectrum Disorders: screening.

Existing law, the Lanterman Developmental Disabilities Services Act, requires the State Department of Developmental Services to contract with regional centers for the provision of various services and supports to persons with developmental disabilities, including Autism Spectrum Disorders (ASD).

Existing law, the California Early Start Intervention Services Act, commonly known as the Early Start program, provides various early intervention services for infants and toddlers who have disabilities or who are at risk of having disabilities to enhance their development and to minimize the potential for developmental delays.

This bill would require the State Department of Developmental Services to partner with at least one regional center to implement a

2-year Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program in at least 3 ~~counties~~ in key geographic areas. The pilot program would establish best practices for early screening, diagnosis, referral, and treatment for children with ASD. The bill would also require the department to establish an advisory committee ~~of stakeholders to assist in coordinating~~ to provide advice regarding the pilot program.

The bill would require the department and the advisory committee, no later than July 1, 2011, to report to the Legislature and the Governor on the pilot program. The bill would establish the Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program Fund in the State Treasury, to be used by the department, upon appropriation by the Legislature, for purposes of this pilot program. The department would be required to apply to the California Children and Families Commission for funding for the pilot program. The pilot program would only be established after that funding, or funding from other sources, excluding General Fund moneys, was obtained. This bill would make its provisions inoperative on July 1, 2011, and repeal them on January 1, 2012.

Vote: majority. Appropriation: no. Fiscal committee: yes.
State-mandated local program: no.

The people of the State of California do enact as follows:

- 1 SECTION 1. The Legislature finds and declares the following:
- 2 (a) The diagnosis of Autistic Disorder, Asperger's Disorder,
- 3 and Pervasive Developmental Disorder Not Otherwise Specified
- 4 all fall under the clinical umbrella term Autism Spectrum Disorders
- 5 (ASD).
- 6 (b) The number of children diagnosed with ASD has grown
- 7 dramatically in recent years and is a serious public health crisis
- 8 that must be addressed. According to the federal Centers for
- 9 Disease Control and Prevention, ASD can now be diagnosed in
- 10 one of every 150 children and can occur in all ethnic, racial, and
- 11 socioeconomic groups.
- 12 (c) Autism Spectrum Disorders are complex neurological
- 13 developmental disorders with onset in early childhood that result
- 14 in substantial impairment in social interaction and communication
- 15 and in the presence of unusual behaviors and interests.

(d) Recent reports and studies have called attention to significant gaps in programs and services for individuals with ASD. Late identification and referral for intervention of young children with ASD, insufficient preparation and reimbursement of health care professionals, and inadequate collaboration between medical, home, and other systems of care that are important in comprehensive intervention are just a few challenges facing children with ASD and their families.

(e) While it is now accepted and supported by research that early screening, diagnosis, and intervention, as well as timely access to services, can improve outcomes and help children with ASD function at higher levels, significant barriers exist to achieving these goals.

SEC. 2. Article 9 (commencing with Section 4699) is added to Chapter 6 of Division 4.5 of the Welfare and Institutions Code, to read:

Article 9. The Autism Spectrum Disorders Early Screening,
Intervention, and Treatment Pilot Program

4699. (a) As used in this article, “ASD” means Autism Spectrum Disorders.

(b) The State Department of Developmental Services shall partner with one or more regional centers to implement a two-year pilot program in at least three ~~counties~~ in key geographic areas around the state that will do the following:

~~(1) Identify solutions to significantly improve the quality of health care for children between birth and five years of age with ASD and their families, with particular attention paid to increasing~~

~~(1) Significantly improve early developmental screening and improving protocols and coordination of referral, diagnostic, and treatment services for children with ASD between birth and five years of age, inclusive.~~

(2) Develop a comprehensive model of best practices for early identification of children with ASD or other developmental delays and effective referral and coordinated followup care, focusing particularly on culturally, linguistically, and geographically diverse or underserved populations.

4699.1. (a) ~~The~~ *In order to achieve the goals of the pilot program, the department shall work with the advisory committee*

1 established pursuant to Section 4699.2, as well as local volunteers,
2 including, but not limited to, regional center staff, health care
3 professionals, ~~local education agency and school district staff~~, and
4 representatives from public and private health insurance companies
5 in the selected counties to ~~achieve the following goals~~ *specifically*
6 *test the following methods*:

7 (1) Use *of* innovative methods to increase early screening for
8 ASD, including, *but not limited to*, the use of parent-completed
9 screening tools, more screening in community settings ~~such as~~
10 ~~child care, schools, and clinics~~, and the use of Web-based tools
11 and those that are compatible with electronic medical records.

12 ~~(2) Improve communication between physicians and families,~~
13 ~~especially when discussing the implications of developmental~~
14 ~~screening test results, with particular focus on mitigating negative~~
15 ~~consequences of widespread developmental screening, such as~~
16 ~~increased parental anxiety or the impact of false positives on~~
17 ~~interaction with the child while the family awaits diagnosis.~~

18 ~~(3) Improve collaboration and communication among medical~~
19 ~~practitioners and local regional centers, Early Start, and local~~
20 ~~educational systems for referral protocols and procedures for~~
21 ~~children with positive screens that include feedback to local health~~
22 ~~care professionals to ensure appropriate medical diagnosis.~~

23 *(2) Implementation of the medical home model to improve*
24 *coordination between physicians, families, regional centers, and*
25 *other entities as it relates to the evaluation, screening, referral,*
26 *and coordination of care and treatment for children with ASD.*

27 ~~(4)~~

28 (3) Use of telehealth and telemedicine strategies for professional
29 development, outreach, and training to primary care physicians,
30 residents in pediatrics and family practice, and medical students,
31 as well as for clinical consultation and to improve access to care
32 in rural sites.

33 ~~(5)~~

34 (4) Use of adequate payment and reimbursement strategies that
35 will facilitate and incentivize routine screening and facilitate
36 collaborative, coordinated, ongoing care to families within the
37 context of a medical home.

38 ~~(6)~~

39 (5) Use of incentives for continuing medical education and other
40 professional training and development and practice improvement

1 to assist physician offices with implementation of universal early
2 development screening, including, but not limited to, selecting,
3 obtaining, and utilizing appropriate and validated screening tools
4 and increasing knowledge of referral protocols and treatment
5 options.

6 ~~(7) Increase public awareness about ASD and the fact that early~~
7 ~~diagnosis and intervention can improve outcomes and increase~~
8 ~~function in children.~~

9 (b) The department and the advisory committee may partner
10 with existing public, private, state, or national initiatives to share
11 information and to avoid duplication of efforts and shall build upon
12 the work and recommendations in recent reports and published
13 models.

14 (c) The Legislature recognizes that the regional center system
15 serves individuals who are deemed eligible pursuant to subdivision
16 (a) of Section 95014 of the Government Code and subdivisions
17 (a) and (l) of Section 4512. Nothing in this article is intended to
18 change existing eligibility requirements for receiving regional
19 center services.

20 4699.2. (a) The department shall establish an advisory
21 ~~committee of stakeholders to assist in coordinating~~ *to provide*
22 *advice regarding* the pilot program. The committee shall meet at
23 least once in person, but shall conduct as much business as possible
24 via conference call and electronic means.

25 (b) The committee shall be composed of representatives from
26 each of the following entities, as well as other interested
27 stakeholders that the department deems necessary:

28 ~~(1) State Department of Education.~~

29 ~~(2)~~

30 ~~(1)~~ State Department of Public Health.

31 ~~(3)~~

32 (2) State Department of Health Care Services.

33 ~~(4)~~

34 (3) State Department of Mental Health.

35 ~~(5)~~

36 (4) Department of Managed Health Care.

37 ~~(6)~~

38 (5) University Centers for Excellence in Developmental
39 Disabilities.

40 ~~(7)~~

1 (6) State Council on Developmental Disabilities.

2 ~~(8)~~

3 (7) Association of Regional Center Agencies.

4 ~~(9)~~

5 (8) The University of California.

6 ~~(10)~~

7 (9) American Academy of Pediatrics.

8 ~~(11)~~

9 (10) California Academy of Family Physicians.

10 (c) There shall be no compensation for the advisory committee
11 except for reimbursement for expenses incurred in the conduct of
12 committee business.

13 4699.3. (a) No later than July 1, 2011, the department, working
14 with the advisory committee, shall provide to the Legislature and
15 the Governor a report on the pilot program. The report shall make
16 recommendations for legislative, regulatory, or fiscal initiatives
17 that would further the goal of early identification and treatment of
18 ASD and other developmental delays.

19 (b) The report shall specifically address all of the following:

20 (1) The change in referral numbers and patterns from baseline
21 historical trends after training in, and implementation of, screening,
22 referral, and assessment protocols.

23 (2) The planning and resource allocation required at the state
24 and federal levels to build capacity in, and ensure access to, the
25 regional center system and Early Start programs to prepare for the
26 influx of autistic children and families that will result from routine
27 screening, ~~such as achieving reasonable wait times after a family~~
28 ~~has been referred for assessment.~~

29 (3) Accessibility and diagnostic evaluation and intervention
30 resources for children identified with ASD.

31 (4) The fiscal impact on health care professionals and regional
32 centers of increased screenings and referrals.

33 (5) Changes in practice patterns for participating physicians,
34 including residents establishing new practices, and other health
35 care professionals.

36 ~~(6) The effectiveness of physicians' developmental monitoring~~
37 ~~and screening efforts over time, as policies to encourage~~
38 ~~developmental screening are implemented.~~

39 ~~(7)~~

1 (6) Cost-effectiveness of routine early screening, referral, and
2 intervention conducted in a coordinated fashion using the medical
3 home model.

4 ~~(8)~~

5 (7) The impact on families in an environment of universal,
6 widespread developmental screening, including the impact of false
7 positives on parent-child interaction.

8 ~~(9)~~

9 (8) Other factors as the department and the advisory committee
10 deem appropriate.

11 (c) The preparation of the report shall be funded through federal,
12 state, or private funds secured with the help of the advisory
13 committee. No state general funds shall be used to prepare the
14 report.

15 4699.4. (a) The Autism Spectrum Disorders Early Screening,
16 Intervention, and Treatment Pilot Program Fund is hereby created
17 in the State Treasury. The department shall deposit any moneys
18 received from the state, federal government, or from private
19 donations into the fund, to be used by the department, upon
20 appropriation by the Legislature, for the pilot program.
21 Notwithstanding Section 16305.7 of the Government Code, interest
22 and dividends on moneys in the fund shall accrue to the fund.

23 (b) No state general funds shall be used to fund the pilot
24 program. The department shall apply to the California Children
25 and Families Commission for funding to cover the pilot program.
26 The pilot program shall be established only after the department
27 has applied to, and obtained funds from, the California Children
28 and Families Commission or other sources.

29 4699.5. This article shall become inoperative on July 1, 2011,
30 and, as of January 1, 2012, is repealed, unless a later enacted
31 statute, that is enacted before January 1, 2012, deletes or extends
32 the dates on which it becomes inoperative and is repealed.